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Children and HIV in Scotland: Findings from a Cross-Sector Needs Assessment of Children and Young People Infected and Affected by HIV in Scotland

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Abstract

This article reports on a study conducted in 2009 and funded by the Elton John AIDS Foundation, which set out to chart the health and social care needs of children and young people infected with, and affected by, HIV in Scotland. The study had three elements: a scoping study, an epidemiological survey of infected and affected children, and young people and interviews with forty-eight informants (practitioners, parents and carers, and infected and affected children and young people). The study indicates that a number of significant changes have taken place since earlier research on infected and affected children and young people in Scotland. Most critically, it is argued that, at the same time as more people than ever are HIV-positive and a new, younger generation of children is living with HIV, so policy directives in HIV and children's services may make the needs of these children invisible. The paper ends by drawing out conclusions for policy and practice.

Keywords: Affected children, infected children, illness, Scotland, HIV

Accepted

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Introduction

Children who are infected with, and affected by, Human Immunodeficiency Virus (HIV) are living with an illness that, throughout the world, brings with it stigma and discrimination. Studies have shown consistently that HIV places a heavy burden on parents and on children and young people within families, in spite of advances in treatment (Mason *et al.*, 2001; Cree *et al.*, 2004b; Reidpath and Chan, 2005). This article will, first, explore the context in which HIV is situated, globally and in Scotland, before going on to present the findings of a recent study that investigated the health and social care needs of children and young people infected and affected by HIV in Scotland. Findings will be compared with earlier research into the needs of Scottish children and young people before implications for policy and practice are discussed.

Definitions

We must begin with some consideration of terminology. The words ‘children and young people’ are used in this paper to refer to all those up to the age of eighteen years, in line with the United Nations Convention on the Rights of the Child and legislation that concerns children in Scotland. However, Health Protection Scotland (HPS), the primary source of data collection on HIV in Scotland, works from the assumption that children are only those up to the age of fifteen years. This inevitably leads to a discrepancy between ‘official’ and other sources of evidence in relation to infected children, as will be explored in our findings.

The words ‘infected’ and ‘affected’ also require clarification. We have avoided describing the children and young people in our study as ‘HIV-positive’ because, although babies born to infected mothers may be technically ‘HIV-positive’, not all go on to develop HIV. Moreover, in a very small number of cases, some babies born HIV-negative go on to develop HIV. Hence, ‘infected children’ is technically a more accurate way of describing children with HIV (Mok, 2009). We use the term ‘affected children’, by contrast, to refer to children and young people who have a caregiver who is HIV-positive but who are not infected with HIV themselves. This is, of course, an artificial distinction, because all infected children are also affected by HIV, because they are likely to be living in families in which someone else is infected with the virus. At the same time, affected children may also be infected with HIV but not yet know this because they have never been tested. It is estimated that between one-quarter and one-third of all those with HIV in the UK and USA do not know about their illness; this number is likely to be much higher in the developing world (BHIVA/CHIVA/BASHH, 2009).

Finally, ‘health’ services will be used throughout this article to refer to all the clinical services available to those who are HIV-positive, including GP practices, dedicated clinics, and general and specialist hospitals. The term ‘social care’ will also be used in its broadest sense, to include statutory children’s services as well as support services provided by voluntary HIV agencies and children’s charities.

The global context

Latest figures suggest that there are around thirty-three million HIV-positive people (adults and children) worldwide. Each year, around 2.7 million people become infected with HIV and two million people die of AIDS-related symptoms (UNAIDS, 2009). Epidemiologists believe that the global percentage of people living with HIV has stabilised since 2000; however, there has been an increase in the overall number of people living with HIV because of the ongoing increase in new infections and because people are living longer thanks to more widely available highly active antiretroviral therapy (HAART) (UNAIDS, 2009). The opportunistic infections that accompany HIV mean that it continues to be a leading cause of death worldwide and the number one cause of death in Africa: 67 per cent of all people known to be living with HIV and 72 per cent of all AIDS-related deaths in 2007 were in Sub-Saharan Africa (UNAIDS, 2009). Interestingly for this study, young people aged fifteen to twenty-four years of age accounted for 45 per cent of all new HIV infections in adults worldwide in 2007. Additionally, 2.4 million HIV-positive women deliver babies each year throughout the world; without intervention, 1,600 children with HIV will be born every day (UNAIDS, 2009).

The Scottish context

There are more people living with HIV in Scotland than ever before, in part because of more effective management of those living with HIV (Scottish Government, 2009). There has also been an increase in testing, leading to earlier diagnosis, particularly in genito-urinary medicine (GUM) clinic settings (HPS, 2009). Recent predictions suggest that, by 2012, the number of people living with HIV and requiring specialist care is likely to increase by 5–13 per cent per year (HPS, 2009). Although the numbers involved may seem relatively low (between 150 and 350 additional persons each year), the financial implications for a small country of five million people are serious. With HIV treatment costing £10,000 a year, annual costs exceed £30 million (www.hivscotland.org). The Scottish government’s HIV Action Plan notes that ‘Providing treatment and care for all those who

require it is one of Scotland's most pressing HIV challenges' ([Scottish Government, 2009](#), p. 7).

HIV and AIDS emerged as a particular concern in Scotland in the mid 1980s, predominantly in two groupings: amongst gay men and intravenous (IV) drug users. Social workers and health practitioners at that time (the corresponding author of this paper was one) found themselves working with individuals, families and neighbourhoods in crisis, and Edinburgh, the capital of Scotland, was known for a time by the unhappy moniker 'the AIDS capital of Europe' (this term first appeared in an article in the *Sunday Telegraph* newspaper in April 1986 and became widely used thereafter). Health and social services geared up to meet the challenge of this new life-threatening illness. New voluntary sector organisations (NGOs) were established to support positive people; statutory social work agencies recruited substitute families for children soon to be bereaved; social workers worked with parents on disclosure and with children on preparation for loss; health practitioners worked with ill and dying adults and children; public health educators engaged in a major programme of sex education. Social work and health literature published in the 1990s demonstrates the focus of this work (see, e.g. [Claxton and Harrison, 1991](#); [Melvin and Sherr, 1993](#); [Batty, 1993](#); [Morton and Johnson, 1996](#); [Mok and Cooper, 1997](#)). By the mid 1990s, research interest had turned to children affected by HIV, with a UK and Scottish study exploring the scale and dimension of problems facing affected children (see Imrie and Coombes, 1996 and [Inglis and Morton, 1996](#)). Research conducted between 1999 and 2002 investigated this in more depth, as 'the Listening to Children in Scotland' study reported on the lives and experiences of children affected by parental HIV from their own point of view ([Cree et al., 2002, 2004a, 2004b, 2006](#); [Tisdall et al., 2004](#)).

The situation of HIV in Scotland has changed markedly since the 1980s and the 1990s. Prevalence has fallen amongst the IV drug-using community in Scotland, because of changes in drug users' behaviour, encouraged by the introduction of needle exchanges issuing free needles. There was also, for a time, a steady decline in new infections amongst gay men and men who have sex with men (MSM), but it is acknowledged that HIV is on the increase in this group again, as some men may have become complacent about HIV and are ignoring 'safe sex' messages ([HPS, 2010](#)). There has also been an increase in heterosexual transmissions, reflecting a new issue that has come to the fore in Scotland. People who have acquired HIV infection abroad, particularly black African people now living in Scotland, are amongst the newer infections ([HPS, 2010](#)). This has been explored in three further studies (see Sinyemu and Baillie, 2006; [Crusaid/Waverley Care, 2007](#); [Cree, 2008](#)).

Change has not simply been about epidemiology; the daily lives of those who are HIV-positive, particularly (but not exclusively) those living in the developed world, has also been transformed in recent years. HIV remains a

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terminal condition. But it is now experienced by many people as a long-term illness that requires daily drug treatment and regular check-ups, arguably like other chronic or long-term conditions. In Scotland, most of those who are HIV-positive are on HAART. The lucky ones amongst them are in relatively good health. Some of the unpleasant side-effects of the early iterations of drug therapies have been resolved, at least for the present time, and, as a result, many of those who gave up work when they first had an HIV diagnosis have returned to the workplace. Critically for this study, many of those who had decided not to become parents have gone on to start their families or to have more children after a break in child-bearing, thus leading to an increase in the number of affected children in Scotland (Health Protection Agency, 2008). Not everyone on HAART feels well, however. For some, complications and side-effects remain overwhelming, leading to inevitable problems with adherence. Moreover, it is widely accepted that even those who are currently living well may have complex health needs as they live longer (Scottish Government, 2009). For those who have come from the developing world to live in Scotland, there are likely to be added difficulties, because the drugs that they have been using (if any) are likely to have been from an earlier, much less successful generation of drug therapies. This unfortunately has a major impact on the likely success of drug treatment now that they are in Scotland (NAM, 2009).

One feature of HIV that has changed little over the years is the widespread ignorance about HIV. The National AIDS Trust (NAT) commissioned a survey of public perceptions in 2000, 2005 and again in 2007. The agency reports that, twenty-five years after the discovery of HIV as a recognised illness, knowledge about HIV is ‘worryingly low among the general public’. The survey found:

- over 90 per cent of the British public do not fully understand how HIV is (and is not) transmitted;
- significantly fewer people in 2007 are able to identify each of the correct ways in which HIV is transmitted than did so in 2000;
- Scotland and London are among the least knowledgeable about HIV (NAT, 2008).

These results hint at a wider problem, already mentioned in reference to gay men and MSM. There is a sense that HIV has gone off the public agenda in Scotland, and yet it has done so at a time when there are record numbers of people who are HIV-positive. This is of great concern for public health, because lack of awareness about HIV is likely to increase vulnerability to infection. It should also be a concern to all those who are working with infected and affected children, because lack of awareness may increase the stigma and discrimination experienced by those living with HIV and, at the same time, reduce the policy and practice response to this marginalised group. This, then, is the backdrop to the present study.

Cross-sector needs assessment

The aims of the current study were to find out how many children in Scotland were infected with, and affected by, HIV in Scotland, and to assess what, if any, their health and social care needs were. The study was funded by the Elton John AIDS Foundation (EJAF) and supported by a steering group of health and HIV agencies in Scotland. It was conducted between February and July 2009. Ethical approval was given by the School of Social & Political Science Research Ethics Committee at the University of Edinburgh. The study employed three fieldwork methods:

- (1) a scoping study focusing on findings from studies conducted in the last ten years;
- (2) an epidemiological survey of infected and affected children;
- (3) interviews with forty-eight informants (practitioners, parents and carers, and infected and affected children).

Each element of the study will now be outlined in more detail.

Scoping study

The purpose of the scoping study was to find out what was already known about children and young people infected and affected by HIV. Searches of electronic citation and journal databases were undertaken, using the key words 'children', HIV' and 'UK', and covering the period from 1999 to 2009. Both health and social science sources were searched: ASSIA, Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (Cinahl Plus), Ingenta, International Bibliography of Social Sciences, JSTOR, Sociological Abstracts, Social Service Abstracts, Web of Knowledge. All relevant papers were read and their references were examined for other papers of interest. These were then followed up using the same criteria as above and, where necessary, this led to further articles and papers. In addition, a web search was undertaken using Google and Google Scholar, uncovering a wider selection of 'grey', non-scientific literature (including unpublished papers, government and voluntary agency reports, newspaper articles, etc.). The formal search strategy was supported by a targeted examination of policy and statistical data identified by members of the steering group, and by following up specific suggestions made by informants during the interviews for the qualitative part of the study.

The scoping study demonstrated that the focus of attention in research, policy and practice has been fairly consistently on those who are infected with the virus: gay men, intravenous drug-using adults, heterosexual adults and, importantly for our study, children with HIV. Research on infected children has explored a range of epidemiological and psychological

factors: the European Collaborative Study, which began in 1987, and the Collaborative HIV Paediatric Study and National Study of HIV in Pregnancy and Childhood (NSHPC), which started some years later, in 1996, have both provided valuable data. There is also extensive ‘grey’ literature that provides additional information, as well as accounts of practitioners and those working in the field of care and treatment of children with HIV.

Research on infected children highlights the increase in numbers of perinatally infected children who now survive into adulthood; earlier and increasing use of highly active antiretroviral therapy HAART has allowed survival rates that were already getting better to improve further (Gibb *et al.*, 2003; Thorne *et al.*, 2002). But this ‘good news’ story brings additional challenges, and research has explored issues such as adherence to medication in adolescence (Ely, 2008; Logan *et al.*, 2003), emotional and behavioural difficulties of infected young people (Gosling *et al.*, 2004; Melvin *et al.*, 2007), sexual health and infected young people (Thorne *et al.*, 2002) and the need for ‘transition ‘services’, located between adult and child provision (Prime *et al.*, 2004). Furthermore, some research has highlighted that it is not known what long-term adverse effects, if any, may arise for children of medication taken to prevent mother-to-child transmission of HIV (Chiriboga *et al.*, 2005; COHERE, 2008; England *et al.*, 2009; Foster *et al.*, 2006; Shanbhag *et al.*, 2005).

Research also demonstrates that the characteristics of infected children have changed in recent years. Many children now present with HIV at an older age and a large proportion are coming from abroad; most new arrivals have not previously received antiretroviral treatment or have received fixed-dose treatments (HPS, 2009; Judd *et al.*, 2007). Studies show that these children and their families face hardship and disadvantage over and above the impact of HIV, arising out of the combined effects of poverty, poor housing, unemployment, discrimination, racism and uncertain immigration status (Conway, 2006; Crusaid/Waverley Care, 2007; Cree, 2008; Sinyemu and Baillie, 2005).

Most of what is known about affected children arises from a number of illuminative, though relatively small-scale, research projects that have explored the views and experiences of parents and children who are affected by parental HIV. Significant examples include the Listening to Children in Scotland study, conducted between 1999 and 2002, and Afraid to Care, on children living with their families in supported housing in London (Lewis, 2001). Both studies demonstrate that, although there have been advances in improved prognosis and treatment, HIV remains a highly troubling and stigmatised illness that impacts negatively on the lives of affected children (Cree *et al.*, 2006). Children want to be treated as ‘normal’ but, while stigma remains, they value highly the opportunity to meet others ‘like themselves’ in specialist services (Cree *et al.*, 2004a, 2004b, 2006). Additionally, cross-country comparisons of young carers in the context of HIV/AIDS (Evans and Becker, 2007, 2009)

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demonstrate that stigma and discrimination are found across the world, despite the social and cultural differences. A recent report raises another area of concern already noted, that some ‘affected’ children may be under-reported, rather than uninfected (BHIVA/CHIVA/BASHH, 2009).

Two further sources of information were examined for the scoping study: the Scottish government’s recent action plan on HIV (Scottish Government, 2009) and Scottish local authority Children’s Services Plans. From these, it was evident that the government’s approach to HIV is to treat it as a ‘manageable’, long-term illness. The focus of attention is squarely on the targeted prevention of HIV and there is little concern for children who are infected or affected by HIV. At the same time, local authority Children’s Services Plans that set out their priorities for supporting children and young people rarely mention HIV; the policy direction reflects the Scottish government’s push towards ‘mainstream’, universal services as part of their Getting it Right for Every Child programme (Scottish Parliament, 2008).

Epidemiological survey: infected children

Evidence from statistical sources and clinicians indicates that the total number of infected children in Scotland is either thirty-five, according to HPS (2009) figures; forty-three, from data to end of 2008 provided by the National Study of HIV in Pregnancy and Childhood (NSHPC) based at the Institute of Child Health in London; or forty-seven, from March 2009 clinical data provided by paediatricians in Scotland. The different figures reflect different timing and methods of data collection; most critically, HPS statistics only cover young people under fifteen years of age, because of a view that those over fifteen may be sexually active, and therefore may become infected with HIV through sexual intercourse. In contrast, NSHPC and paediatricians include all those under eighteen years of age, although even their figures are different, because of the time-lag in NSHPC producing its statistics. **Q5**

A number of specific issues emerge from these findings. First, it is self-evident that the number of children infected with HIV in Scotland is low. This makes it difficult to justify providing specialist services, for example, for adolescents, who pass on from the relative security of children’s hospital services to adult (GUM) services at fourteen years of age. Low numbers are also an issue for children (and indeed for health and social care workers) who live outside the main centres of population, because GPs and social workers are unlikely to have the necessary specialist knowledge to support infected children when they see so few of them.

Second, NSHPC data to end 2008 indicate that there have been no children born to diagnosed HIV-positive women in Scotland since 2001. This is as a direct result of the introduction of HIV testing of pregnant women and successful treatment of women who are known to be HIV-positive during

pregnancy and childbirth. However, this claim is not altogether accurate. A small number of women refuse to be tested each year (5 per cent in 2009). Two children were born with HIV in the West of Scotland in recent years, one of whom subsequently died (report by clinician, 20 October 2009).

Third, more detailed analysis of the data shows that there are now two distinct groups of children and young people infected with HIV in Scotland: younger children who were born abroad, most often in Africa, and British-born young people who are older, born before routine testing and preventive treatment. Table 1 presents HPS's data in relation to this.

Available evidence also shows special pressure on parts of Scotland in relation to HIV, with NHS Greater Glasgow & Clyde and NHS Lothian treating the largest number of HIV-infected people and young people (Johnman, 2009). This raises new issues for the delivery of services and for the training of health and social care practitioners in Scotland.

Epidemiological survey: affected children

Reaching an accurate estimate of the number of affected children in Scotland is difficult, because these figures are not routinely collected. An estimate from the mid 1990s suggested that there were 626 affected children in Edinburgh, Glasgow and Dundee (Imrie and Coombes, 1995). Another study by Inglis and Morton (1996) put this figure higher: 741 for the three cities and 911 for Scotland as a whole. Replicating Inglis and Morton's methodology, a questionnaire survey was sent to thirteen HIV service providers, asking for information about children and young people whom they knew to be affected by parental HIV. The agencies were as follows:

- four in Edinburgh: the Royal Hospital for Sick Children, Waverley Care, Positive Help, and the Regional Infectious Diseases Unit at the Western General Hospital;
- five in Glasgow: HIV-AIDS Carers and Family Service Provider Scotland, the Brownlee Clinic, Royal Hospital for Sick Children (Yorkhill Hospital), Terrence Higgins Trust, and Waverley Care's African Health Project;
- four other agencies: Terrence Higgins Trust (Aberdeen), Ninewells Hospital (Dundee), and Grampian and Highland Health Boards.

The agencies provided data in relation to 711 children. Extrapolating this Scotland-wide (using Health Board figures for HIV-positive adults), we were able to estimate that there were around 833 affected children in Scotland as a whole. This is, of course, only a guesstimate, because, like the previous counting exercise, it is built on data gathered in relation to adults already using services and so cannot tell us anything about those who are not using services. Just as critically, not all service providers keep records of affected children; HIV and GUM clinics are a significant example of

Table 1 Ethnic origins of HIV-infected children (under age fifteen) living in Scotland (as at 31 March 2009)

| Ethnicity | | Number of cases |
|-----------------------|--|-----------------|
| White (Scottish) | | 3 |
| White (other British) | | 1 |
| White (other) | | 1 |
| Black African | | 24 |
| Mixed | | 4 |
| Unknown | | 1 |
| Total | | 35 |

Source: HPS data, as at 31 March 2009.

this. Of course, many of those born to HIV-positive parents will now be in their late teens or twenties (their parents were infected in the 1980s and 1990s). Because of this, they are less likely to be involved with the HIV agencies that are supporting their parents. All of this suggests that the true figure of affected children and young people in Scotland is likely to be substantially higher than our estimate. It has been calculated that there are between 15,000 and 20,000 affected children in the UK as a whole (Conway, 2006), adding weight to the idea that the ‘real’ figure in Scotland is much higher.

In spite of the lack of certainty over the scale of the problem, significant issues emerge from the survey. Importantly, the data show shifts in pressure on Health Board areas between 1996 and 2009, as demonstrated in Table 2.

We can see here that, while numbers of affected children have declined in Lothian and Tayside (Lothian continues to have the second largest number of affected children in Scotland), they have increased in Greater Glasgow & Clyde Board. The decrease in Lothian and Tayside is likely to be associated with the known decline in HIV amongst IV drug users in Scotland (HPS, 2009); the increase in Greater Glasgow & Clyde reflects (as we will see) Q6

Table 2 Comparisons between 2009 and 1996 figures (1996 figures in brackets)

| Age | Lothian | | Greater Glasgow & Clyde | | Tayside | | Total | |
|---------|---------|--------|-------------------------|--------|---------|--------|-------|--------|
| | 2009 | (1996) | 2009 | (1996) | 2009 | (1996) | 2009 | (1996) |
| 0–4 | 78 | (59) | 93 | (22) | 13 | (37) | 27% | (16%) |
| 5–11 | 107 | (229) | 131 | (47) | 38 | (107) | 41% | (52%) |
| 12–15 | 48 | (63) | 55 | (32) | 25 | (69) | 19% | (22%) |
| 16–18 | 16 | (15) | 47 | (8) | 14 | (32) | 11% | (7%) |
| Unknown | 2 | (18) | 10 | (2) | 0 | (1) | 2% | (4%) |
| Total | 251 | (384) | 336 | (111) | 90 | (246) | 100% | (100%) |

Source: Cree and Sidhva, 2009, p. 29.

the placement in recent years of asylum seekers and refugees in accommodation in the West of Scotland (see www.icar.org.uk/). The findings also demonstrate a change in the age distribution of children, with a much greater number of under-fives in both Lothian and Greater Glasgow & Clyde, and many older teenagers in Greater Glasgow & Clyde, whilst the number in Tayside has fallen. The very young children found by the survey were almost all children of black African mothers, as will be discussed further in the qualitative findings.

Qualitative study

The qualitative study was informed, in large part, by the researchers' previous experience of conducting research on women with HIV (Sidhva, 2004) and on children affected by HIV (Cree *et al.*, 2002, 2004a, 2004b, 2006). Interviews were carried out with a range of stakeholders who could tell us about the health and social care needs of children infected and affected by HIV in Scotland. Forty-eight people were interviewed in total:

- ten social care practitioners from voluntary-sector HIV agencies and children's charities and ten health practitioners from NHS services in Edinburgh, Glasgow, Dundee and Aberdeen;
- sixteen parents and carers from Edinburgh and Glasgow;
- five children and young people infected with HIV and seven children and young people affected by parental HIV from Glasgow and Edinburgh.

The interviews with practitioners were relatively easy to organise. All had been working in the field of HIV in Scotland for a considerable time. Some were members of our Steering Group; some were recommended to us by Steering Group members; many were known to us from previous research. The process of identifying, engaging with and then interviewing parents and children was, in contrast, lengthy and, at times, difficult. First, health practitioners and HIV agency workers approached parents and told them about the study, sharing with them written information about the study's aims and methods. Parents who agreed to take part were then asked whether we might also discuss the study with their children. Some agreed, but many did not. Children and parents were met on at least one occasion prior to interviews taking place, so that information could be shared and consent given. Interviews often had to be rescheduled because informants' lives were not settled. We were pleased that sixteen parents and twelve children were willing to speak with us about such a sensitive topic within the time-scale of our project deadlines.

Most interviews were with individuals or occasionally with two practitioners together. One group interview was also held in Glasgow with

parents and carers. All the interviews (except one with a practitioner) were conducted by the research assistant. They were set up as semi-structured interviews in response to the need to get specific information in relation to existing services and identified needs. In practice, however, they were not rigidly structured and the researcher adopted an open approach (Gray, 2009), which allowed her to step away from the interview schedule if, for example, an informant became distressed or had a lot to say in relation to a particular topic. On two occasions, she agreed to stop the interview and meet the informant on another occasion. The researcher allowed time for debriefing after the formal 'interview' discussion in every instance. All interviews were recorded using an MP3 digital recorder and transcribed for future analysis.

Interviews with practitioners showed that, with the exception of health services, HIV agencies in Scotland are focused on adults; where services for children exist, these must be accessed through adults first. Furthermore, targeted services for children are scarce across Scotland; all practitioners identified the importance of offering safe, non-threatening services to children infected and affected by HIV, particularly given the stigma that surrounds HIV. The practitioners were also concerned about the extreme needs of African families in Scotland faced by HIV. Some noted that inter-agency collaboration was made difficult by pressures on agencies and by issues of confidentiality. All felt that more should be done in schools and in health services to highlight the issues faced by children in relation to HIV. Health practitioners expressed concern about teenagers accessing adult HIV services and argued for the development of transitional services for these young people.

All the parents and carers in the study said that they were worried about how best to support their child. A principal issue was disclosure: how, when and what to tell their child about HIV (either their own HIV status or their child's) and who else could, and should, be told what, and when. They asked for help to be able to discuss HIV more easily with their children. Parents and carers also spoke about the negative impact of stigma 'by association' and the fear this places on their children. They were also all concerned about the lack of services for children infected and affected by HIV, as well as for HIV-positive women. They stressed that giving support to parents may also lead to psycho-social improvements in the quality of life for children.

The infected children and young people who were interviewed were at pains to present themselves, their lives and HIV as 'normal', in spite of their very troubled backgrounds and current hardships. One eleven-year-old black African child who had arrived in Scotland within the previous few months put this as follows:

I want to be like the others in my class, same well like them, same well like other children's.

Another fifteen-year-old black African young woman confirmed this view. She said:

People just try to make the world so complicated, but everything is normal if you want it to be. . . . HIV is just normal, you don't have to make a fuss about it—like on TV when they talk about HIV, they just try to make out as if it's the end of the world, but it isn't.

She had been cared for by an elder sibling since they had come to the UK two years before; both her parents were dead. She remembered being told about her HIV status when she was eleven or twelve and said that she had felt quite unwell recently, not because of HIV, but because of new, stronger medication. This young woman demonstrates that, for some young people, medication may be the one reminder that they have the virus. A thirteen-year-old boy agreed. He said he was having a difficult time with his medication, which sometimes gave him 'an upset tummy' and made him feel sick. But he said he was willing to stick with it for now. Another youth (aged fifteen) said that he had heard from a young person whom he had met on an outing with a befriender about the advantage of having a gastronomy tube fitted so that medicine could go straight into the stomach. He had raised this with his doctor, who agreed to arrange this for him and, although the operation was painful and, to start with, he was afraid to do certain things, he said he was now able 'to do everything that I usually do'.

The wish for life to be 'normal' is, of course, part and parcel of adolescence. Adolescents will do almost anything not to be seen as different from their peers (see [Coleman and Hendry, 1999](#)). The need to be seen as 'normal' is also, however, a strong indicator of the presence of stigma. Significantly, none of the children and young people was able to talk about their illness outside a very small, strictly defined zone of safety, for fear of prejudice or reprisal. One sixteen-year-old white Scottish young woman told the following story:

I told my friend one time when I was younger that my mum was not well . . . we ended up falling out and she pure used it against me and things, so I never told anybody after that. And I never spoke to her, so I just don't know, I just don't tell people.

One white Scottish boy (aged sixteen) said that he was unable to talk to the one person who knew about their HIV (his mother), because he did not wish to upset her.

The children and young people showed ambivalence towards support services. Some did not wish to be singled out for specialist services; one young person went so far as to say that talking about worries made things worse. All of them wanted opportunities to have fun and forget about HIV for a while, but they also said that it was good to be able to talk to others in the same position as themselves. One youth (white Scottish, aged sixteen) said that he did not feel comfortable accessing either children or adult

services, because the latter was a ‘bit babyish, but the adult hospital is a bit too adult’.

The affected children and young people who took part in the study said that they lived with fear and uncertainty, never sure when a parent would become ill or die, yet they wanted, like the infected children and young people, to be seen as ‘normal’ children, with ‘normal’ parents. They spoke about the good times in their lives: about playing with friends and going to youth clubs, about looking after their pets and marching with Majorettes (a dance troupe). They also spoke about being bullied (not just because of HIV in the family) and one young African man (aged thirteen) talked about racist graffiti being daubed on the front door of his flat.

The children and young people also described lives that were full of disruption and loss. They lived in poverty and had experienced many changes of school, neighbourhood and friends, as well as parental separation and the loss of grandparent, parent and even, on two occasions, both parents. One boy (white Scottish, aged twelve) expressed his feelings of loss as follows:

When my mum passed away I was grieving quite a lot . . . I didn’t really mind about HIV until her death, it didn’t really strike me till then, I just got really emotional.

HIV was, for those children and young people, not simply an added burden; it was one that has to be kept secret and that never went away, even after a parent had died. One white sixteen-year-old told us that she cannot tell people about the cause of her mother’s death even now, two years later; she always says that her mum died of ‘liver failure’. She went on to explain further:

[My life] was quite different to other children. I mean, everybody’s got their problems. I just feel that because mine was such a big secret, I couldn’t tell anyone about it.

In common with the infected children, affected children and young people were cautious about whether additional services would help. They said that support should be available to all children and young people, but they also called for more specialised services so that they could be free to talk about HIV in a safe environment. As one young man (white, sixteen years of age) clarified:

I don’t think there should be something to separate HIV people from, like, other people . . . cause that’s going to make them feel like a bit selected or something else.

Reviewing the findings from the interviews, we are left with a paradox. Practitioners, parents and children all stressed that children and young people need to be treated as ‘normal children’, the same as every other child and young person. But they also valued specialist services and urged that these should be available across Scotland. The call to treat children ‘the same’ speaks to the current policy thrust of the Scottish

government in its focus on universal services for children, demonstrated in Getting it Right for Every Child (GiRfEC), first launched in 2004. It aims to 'remove the obstacles that can block children's paths on their journey from birth to adulthood'. It will do this by adopting 'a common, coordinated approach across all agencies that supports the delivery of appropriate, proportionate and timely help to all children as they need it' ([Scottish Parliament, 2008](#)). GiRfEC has been put into practice across Scotland through the introduction of Local Authorities' Integrated Children's Services Plans. These plans make little or no mention of HIV. But will mainstream agencies have enough knowledge and experience, and enough lack of prejudice, to be able to give adequate psycho-social and bio-psycho-social support to infected and affected children and young people in universal services? Furthermore, if children and young people are advised by their parents not to tell anyone about HIV, how will they be able to access the help they need from mainstream services? These questions remain critical for the future.

Conclusion

HIV in Scotland has changed radically since research was first carried out into children's experiences. There are more people living with HIV and, significantly, a new population of black Africans in Scotland who are HIV-positive. More young people are presenting with HIV at an older age and, at the same time, there are more under-five-year-olds who are infected with HIV. Infected and affected children want to be treated as 'normal', but, as the earlier studies showed, they are living with a family illness that they cannot talk about and, because of this, their lives are far from 'normal'. We have suggested that it is unlikely that generalist practitioners in either health or children's services will have the necessary confidence or expertise to support the small numbers of children and young people (infected or affected) who come their way. In addition, whilst the government focuses on public education and on paying ever-increasing sums for medication, it remains to be seen whether the needs of these children and young people will ever be a priority. It is vital, therefore, that specialist voluntary-sector HIV agencies are given the financial support they need to develop services to support these children and young people in the future.

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References

- Batty, D. (ed.) (1993) *HIV Infection and Children in Need*, London, BAAF.
- BHIVA/CHIVA/BASHH (2009) 'Don't Forget the Children': *Guidance for the HIV Testing of Children with HIV-Positive Parents*, available online www.bhiva.org/.
- Chiriboga, C. A., Fleishman, S. C., Gaye-Robinson, L. and Abrams, E. J. (2005) 'Incidence and prevalence of HIV encephalopathy in children with HIV infection receiving highly active anti-retroviral therapy (HAART)', *Journal of Pediatrics*, **146**(3), pp. 402–7.
- Claxton, R. and Harrison, T. (eds) (1991) *Caring for Children with HIV and AIDS*, Sevenoaks, Edward Arnold.
- Coleman, J. and Hendry, L. B. (1999) *The Nature of Adolescence*, 3rd edn, London, Routledge.
- Collaboration of Observational HIV Epidemiological Research Europe (COHERE) Study Group (2008) 'Response to combination antiretroviral therapy: Variation by age', *AIDS*, **22**, pp. 1463–73.
- Conway, M. (2006) *Children, HIV, Asylum and Immigration*, London, National Children's Bureau.
- Cree, V. E. (2008) 'It's Good to Go for a Test': *Report of the Evaluation of Waverley Care's HIV Testing Campaign in Glasgow*, Edinburgh, Waverley Care.
- Cree, V. E. and Sidhva, D. (2009) 'I Want to Be Like the Others': *A Cross-Sector Needs Assessment of Children Infected and Affected by HIV in Scotland*, Edinburgh, Waverley Care.
- Cree, V. E., Kay, H. and Tisdall, K. (2002) 'Research with children: Sharing the dilemmas', *Child and Family Social Work*, **7**(1), pp. 47–56.
- Cree, V. E., Kay, H., Tisdall, K. and Wallace, J. (2004a) 'Social support and children affected by parental HIV', *European Journal of Social Work*, **7**(2), pp. 195–210.
- Cree, V. E., Kay, H., Tisdall, K. and Wallace, J. (2004b) 'Stigma and parental HIV', *Qualitative Social Work*, **3**(1), pp. 7–25.
- Cree, V. E., Kay, H., Tisdall, K. and Wallace, J. (2006) 'Listening to children and young people affected by parental HIV: Findings from a Scottish study', *AIDS Care*, **18**(1), pp. 73–6.
- Crusaid/Waverley Care (2007) *Poverty and HIV*, Edinburgh, Waverley Care.
- Ely, A. (2008) *Looking after HIV: Considering the Needs of HIV Positive Looked After Children*, London, National Children's Bureau.
- England, K. and Thorne, C., European Collaborative Study (2009) 'Use of neonatal anti-retroviral prophylaxis for prevention of mother-to-child transmission of HIV is decreasing in Western Europe', *Clinical Infectious Diseases* **15**, **48**(12), pp. 1797–800.
- Evans, R. and Becker, S. (2007) *Hidden Young Carers: The Experiences, Needs and Resilience of Children Caring for Parents and Relatives with HIV/AIDS in Tanzania and the UK: Stakeholder Report Executive Summary*, Nottingham, School of Sociology and Social Policy, University of Nottingham.
- Evans, R. and Becker, S. (2009) *Children Caring for Parents with HIV/AIDS: Global Issues and Policy Responses*, Bristol, The Policy Press.

- Foster, C. J., Biggs, R. L., Melvin, D., Walters, M. D. S., Tudor-Williams, G. and Lyall, E. G. H. (2006) 'Neurodevelopmental outcomes in children with HIV infection under 3 years of age', *Developmental Medicine & Child Neurology*, **48**, pp. 677–82.
- Gibb, D., Duong, T., Tookey, P. A., Sharland, M., Tudor-Williams, G., Novelli, V., Butler, K., Riordan, A., Farrelly, L., Masters, J., Peckham, C. S. and Dunn, D. T. (2003) 'Decline in mortality, AIDS, and hospital admissions in perinatally HIV-1 infected children in the United Kingdom and Ireland', *British Medical Journal*, **327**, pp. 1019–24.
- Gosling, A. S., Burns, J. and Hirst, F. (2004) 'Children with HIV in the UK: A longitudinal study of adaptive and cognitive functioning', *Clinical Child Psychology and Psychiatry*, **9**(1), pp. 25–37.
- Gray, D. E. (2009) *Doing Research in the Real World*, 2nd edn, London, Sage.
- Health Protection Agency (HPA) (2008) *HIV in the UK: 2008 Report*, December 2008, available online at www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1227515299695/.
- ~~Health Protection Scotland (HPS) (2008) *Focus: HIV in Scotland 2007: Review. HPS Q8 Weekly Report*, 42: 08/04, available online at www.hps.scot.nhs.uk/bbvsti/.~~
- Health Protection Scotland (2009a) *Focus: HIV in Scotland, 2008: Review. HPS Weekly Report*, 4 February, 43: 09/05, available online at www.hps.scot.nhs.uk/bbvsti/.
- Health Protection Scotland (2009b) *HIV Infection and AIDS: Quarterly Report to 31 March 2009 (ANSWER)*, available online at www.hps.scot.nhs.uk/ewr/.
- Health Protection Scotland (2010) *HIV Infection and AIDS: Quarterly Report to 31 March 2010 (ANSWER)*, available online at www.hps.scot.nhs.uk/ewr/.
- Imrie, J. and Coombes, Y. (1995) *No Time to Waste: The Scale and Dimension of the Problem of Children Affected by HIV/AIDS in the United Kingdom*, London, Barnardos.
- Inglis, S. and Morton, S. (1996) *Children Affected by HIV in Dundee, Edinburgh and Glasgow*, Edinburgh, Children in Scotland.
- Johnman, C. (2009) *Treatment and Care Needs Assessment: People Living with HIV, Scottish Public Health Network (ScotPHN) Report: Draft For Stakeholder Review (09/03/09–08/04/09)*, Edinburgh, ScotPHN.
- Judd, A., Doerholt, K., Tookey, P. A., Sharland, M., Riridan, A., Menson, E., Novelli, V., Lyall, E. G. H., Masters, J., Tudor-Williams, G., Duong, T. and Gibb, D. M. (2007) 'Morbidity, Morality, and Response to Treatment by Children in the United Kingdom and Ireland with Perinatally Acquired HIV Infection during 1996–2006: Planning for Teenage and Adult Care', *Clinical Infectious Diseases*, **45**(1 October), pp. 918–24.
- Lewis, E. (2001) *Afraid to Say: The Needs and Views of Young People Living with HIV/AIDS*, London, National Children's Bureau.
- Logan, D., Zelikovsky, N., Labay, L. and Spergel, J. (2003) 'The Illness Management Survey: Identifying adolescents' perceptions of barriers to adherence', *Journal of Pediatric Psychology*, **28**(6), pp. 383–92.
- Mason, T., Xarlisle, C., Watkins, C. and Whitehead, E. (eds) (2001) *Stigma and Social Exclusion in Health Care*, London, Routledge.
- Melvin, D. and Sherr, L. (1993) 'The child in the family: Responding to AIDS and HIV', *AIDS Care*, **5**(1), pp. 35–42.
- Melvin, D., Krechevsky, D., Divac, A., Tacconelli, E., Miah, J. and Waugh, S. ~~et al.~~ (2007) **Q9** 'Parental reports of emotional and behavioural difficulties on the SDQ for school-age

children with vertically acquired HIV infection living in London', *Psychology, Health & Medicine*, **12**(1), pp. 40–7.

Mok, J. (2009) Personal correspondence, October.

Mok, J. and Cooper, S. (1997) 'The needs of children whose mothers have HIV infection', *Archives of Disease in Childhood*, **77**, pp. 483–7.

~~Morris, K. (ed.) (2008) *Social Work and Multi-Agency Working: Making a Difference*, Q10
Bristol, BASW/Policy Press.~~

Morton, S. and Johnson, D. (eds) (1996) *Children and HIV: Supporting Children and their Families*, Edinburgh, The Stationery Office.

NAM (2009) *HIV & AIDS Treatment in Practice*, 148, November, available online at www.aidsmap.com.

National AIDS Trust (NAT) (2008) *Public Attitudes Towards HIV*, London, NAT, available online at www.nat.org.uk/.

Prime, K. P., Jungmann, E. A. and Edwards, S. G. (2004) 'Decline in morality in children with HIV in the UK and Ireland: HIV positive adolescents urgently need dedicated services', *British Medical Journal*, **328**(February), p. 524.

Reidpath, D. D. and Chan, K. Y. (2005) 'A method for the quantitative analysis of the layering of HIV-related stigma', *AIDS Care*, **17**(4), pp. 425–32.

Scottish Government (2009) *HIV Action Plan in Scotland, September 2009 to March 2014, Final Draft 10 August 2009*, Edinburgh, Scottish Government.

Scottish Parliament (2008) *Getting It Right for Every Child*, Edinburgh, Scottish Government, available online at www.scotland.gov.uk/Topics/People/Young-People/childrensservices/girfec/.

Shanbhag, M. C., Rutstein, R. M., Zautis, T., Zhao, H., Chao, D. and Radcliffe, J. (2005) 'Neurocognitive functioning in pediatric human immunodeficiency virus infection: Effects of combined therapy', *Archives of Pediatric Adolescent Medicine*, **159**(7), pp. 651–6.

Sidhva, D. (2004) 'Living with HIV/AIDS: Turning points, transitions and transformations in the lives of women from Bombay and Edinburgh', unpublished Ph.D. dissertation, University of Edinburgh.

Sinyemu, E. and Baillie, M. (2005) *HIV Becomes Your Name*, Edinburgh, Waverley Care.

Thorne, C., Newell, M. L., Botet, F. A., Bohlin, A. B., Ferrazin, A., Giaquinto, C., de José Gomez, I., Mok, J. Y., Mur, A. and Peltier, A. (2002) 'Older children and adolescents surviving with vertically acquired HIV infection', *Journal of Acquired Immune Deficiency Syndromes*, **29**, pp. 396–401.

Tisdall, E. K. M., Kay, H., Cree, V. E. and Wallace, J. (2004) 'Thinking positively: Listening to children and young people whose parent or carer is HIV positive', *British Journal of Social Work*, **34**(8), pp. 1097–115.

~~UNAIDS (2008) *Report on the Global AIDS Epidemic*, available online at www.unaids.org/. Q11~~

UNAIDS (2009) *AIDS Epidemic Update*, available online at www.unaids.org/.

WHO/UNAIDS/UNICEF (2009) 'Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector', available online at www.unaids.org/pub/Report/2009/20090930_tuapr_2009_en.pdf. Q12

Q13